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Vigilant attentiveness in families observing deterioration in the dying intensive care patient: a secondary analysis study.

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ABSTRACT

Background: Family support in intensive care is often focussed on what information is communicated to families. This is particularly important during treatment withdrawal and end of life care. However, this positions families as passive receivers of information. Less is known about what bereaved family members actually observe at end of life, and how this is interpreted.

Aim: Secondary analysis study was conducted in order to explore the concept of vigilant attentiveness in family members of adult patients dying in intensive care.

Method: Secondary analysis of 8 interviews sorted from 2 primary data sets containing 19 interviews with 25 bereaved family members from two intensive care units in England was undertaken. Directed content analysis techniques were adopted.

Findings: Families are observant for physiological deterioration by watching for changes in cardiac monitors as well as paying attention to how their relative looks and sounds. Changes in treatment/interventions were also perceived to indicate deterioration.

Conclusion: Families are vigilant and attentive to deterioration, implying that families are active participants in information gathering. By clarifying what families notice, or do not notice during the dying trajectory in ICU, health care professionals can tailor information, helping to prepare families for the death of their relative.

Keywords [4-10 - alphabetical]

Death and dying; end of life care; families; intensive care

Implications for Clinical Practice [3-4 bullet points]

- The quality of information given to families and the understanding of families about death and dying impacts on health outcomes of bereaved family members. It is important that families are prepared and informed about death and dying in intensive care.
- The concept of 'vigilant attentiveness' can inform how doctors and nurses assess family understanding and comprehension of deterioration at end of life.
- By asking pertinent questions about what families notice, and do not notice about their relative at end of life, health care professionals can refine their communication style, tailoring the information provided to family members in preparation for death.

Introduction and background

Effective communication between health care professionals and family members of dying intensive care patients is an essential component of high quality end of life care (Treece, 2007). Poor communication with families has been identified as contributing to: family anxiety and depression post death (Azoulay, 2002; Scheunemann et al., 2011); lower levels of family satisfaction with care (Wall, 2007); low levels of family comprehension regarding the patient's

condition (Azoulay et al., 2000; Rodriguez et al., 2008), and conflicts between family members and health care team (Fassier and Azoulay, 2010).

Communication with families is an essential, if frequently under-appreciated aspect of the critical care nurses' role (Lind et al., 2012). Nurses act as information brokers and communication facilitators (Bloomer et al., 2013), and use communication to build relationships with families enable the support of families (Slatore et al., 2012). It is therefore unsurprising that Adams' et al. (2015) call for further work to be conducted on how nurses work with families in order to understand the communication processes used in critical care settings.

This would clearly meet the needs of families as studies report that family members want more frequent and effective communication with nurses and doctors (Pochard et al. 2005) especially in relation to end of life care (Breen et al., 2001); this includes involvement in shared decision-making about treatment decisions at end of life (Arnold and Kellum, 2003; Azoulay, 2005; White et al., 2007). However, literature on the experience and communication needs of family members at end of life focusses on the role of the health care professional in assessing family information needs (Luce, 2010) and providing information whilst managing family expectations (Curtis and White, 2008). This focus may lead to the perceptions that family members are passive receivers of information, largely unaware of the progress of their relative (Azoulay, 2000).

However, there is literature suggesting that family members are active seekers of cues or signs as to what is happening to their relative, and that family members in intensive care are in a state of vigilant attentiveness described as "a focussed, persistent, and diligent watchfulness" (Bournes and Mitchell 2002, p:62). Although the concept of vigilant attentiveness was originally developed to describe family members' experiences of being in an Intensive Care waiting room, this concept engaged and stimulated our thinking. This prompted us to consider 'testing' this concept in relation to families' awareness of deterioration in their dying relative.

Study design

A secondary analysis was undertaken to explore the concept of vigilant attentiveness in family members of adult patients dying in intensive care. The dataset for this study was generated from two primary studies that interviewed bereaved family members in the context of family experiences and end of life in the intensive care environment.

Secondary analysis is an approach of generating new knowledge from existing data sources. Whilst secondary analysis of primary data is a familiar concept within the positivist paradigm (Fielding, 2000), it is less common in the naturalistic paradigm. Unlike the re-use of archived data, secondary analysis of data suggests that data has a contemporary relevance and is therefore carried out for specific reasons. Secondary analysis offers many benefits to researchers including the: generation of new knowledge from existing datasets previously analysed (Long-Sutehall et al., 2010); opportunity to apply a new perspective or a new conceptual focus (Heaton, 1998) in preparation for further research; enabling of training and development for novice researchers (Glaser, 1963). Furthermore secondary analysis is of

particular ethical and economic value if the topic under investigation is of a sensitive nature (Fielding 2004), for example, family experience of death and dying.

Study methods

Prior to undertaking data analysis, the original datasets were assessed to determine whether data had potential to address the research aim (Heaton, 2004). A quality assessment was undertaken by sorting data from the two primary studies that had interviewed bereaved family members.

Primary Datasets

Study One: Coombs, M.A., Long-Sutehall, Tracy and Addington-Hall, J. (2012) Challenges in transition from intervention to end of life care in intensive care: a qualitative study.
Study One completed in-depth interviews with 33 health care staff (n=26) and relatives (n=7) of 18 non-survivors in two intensive care settings (general adult ICU, cardiac ICU) in England. The 18-month study (2008 - 2009), funded by the Research for Patient Benefit Fund, aimed to investigate factors influencing end of life decision-making and treatment withdrawal in Intensive Care from the perspective of participating doctors, nurses, and bereaved family members.

Study Two: Coombs, M.A. (2015) What is Important to Families in Intensive Care Once a Decision has been Made to Withdraw Treatment.
Study Two completed 17 in-depth interviews with 21 family members whose relative had died in one general intensive care unit in England. This 12-month study (2012), funded by the National Institute for Health, aimed to investigate the experience and needs (support and communication) of families during end of life care in adult intensive care.

Secondary use of data – ethics

NHS National Research Ethics Service approval had been gained for the both primary studies (Dataset 1: 08/H0501/65, Dataset 2: 11/SC/0338) with the consent forms requesting participant agreement for the re-use of primary data in secondary analysis. Discussion with the Human Ethics Committee at Victoria University of Wellington confirmed that no further ethical review was required (personal communication).

Method

To guide secondary analysis, a four stage process was undertaken (Table 1) including primary dataset sorting, transcript review, coding and conceptual analysis.

Table 1: Stages and outcomes of the secondary analysis method

Stages in analysis	Actions	Guiding questions/criteria/aim	Outcomes
Stage 1	Sorting of the primary datasets	Characteristics of the study populations; alignment with research design used; data being available whereby participants commented on or made observations related to any aspect of deterioration in their dying relative	8 transcripts including 11 participants
Stage 2	Review of included transcripts	Searching for word, word sense, phrase, sentence, or theme referring family perceived signs of deterioration	Initial coding list
Stage 3	Coding/categorisation	Establishing the existence and frequency of concepts in the text	30 codes allocated Two categories created:

			I) physiological (subcategories: visual cues and auditory cues) II) Looks (subcategories: colour, appearance, responsiveness)
Stage 4	Conceptual analysis	Making inferences (process of inferring things based on what is already known).	

Sorting and review of the primary data

Stage 1: The primary datasets were brought together and assessment made of the initial study designs and methods. All interviews were carried out face-to-face using a semi-structured interview guide. Interviews were recorded using a digital voice recorder with interview data transcribed verbatim. The transcribed data underwent thematic analysis. All the interviews with bereaved families undertaken in Study One (n = 7) and Two (n = 17) were available as audio recordings and as transcribed reports. The field and researcher notes from both studies were available as electronic word documents.

Stage 2: The two primary datasets were reviewed by members of the research team (MC, TLS) and an assessment regarding fit of the two datasets for this secondary analysis study was made. The assessment was based on: similarities in the characteristics of the study populations, alignment of the research designs used, and sufficient in-depth data being available (Heaton, 2004). Interviews were included in the review if participants commented on or made observations related to any aspect of deterioration in their dying relative.

Outcome of sorting: Following review, two interviews from Primary Dataset One were included in the secondary analysis. Five interviews contained minimal reference to awareness of deterioration and were excluded. Of the 17 interviews from Primary Dataset Two, six were found to have data pertinent to the research question and were included. This resulted in eight interviews that had been undertaken with 11 bereaved family members (Table 2) being included in the secondary analysis.

Table 2: Bereaved family member interviews included from Dataset 1 and 2

Initial subject Code	Secondary analysis code	Patient details	Family member(s) interviewed
Dataset 1:			
WS31 0022	SA 001	Male, age 69. Type II respiratory failure. Implantable defibrillator.	Wife and son
WS31 0026	SA 002	Female, age 75. Urosepsis, cardiac surgery	Son and daughter in law
Dataset 2:			
WS450003	SA 003	Male, age 77. Respiratory failure post gastric surgery.	Daughter
WS450005	SA 004	Female, age 68. Intracerebral bleed.	Husband
WS450006	SA 005	Female, age 76. Multisystem failure. Pneumonia.	Friend
WS450007	SA 006	Female, age 82. Multisystem failure post abdominal surgery.	Daughter

WS450012	SA 010	Male, age 72. Respiratory failure post cardiac surgery.	Wife
WS450013	SA 011	Male, age 55. Multisystem failure. Lymphoma.	Wife and son
WS450023	SA 018	Male, age 79. Cardiac event with pulmonary fibrosis.	Son and daughter

Data Analysis

Stage 3: Once the suitability of the datasets had been determined, the 8 sorted transcripts were then read sequentially by TLS and JT. Re-coding was undertaken generating new coding lists and memos. No codes were used from the primary analysis. Data analysis was a deductive process applying top down or directed qualitative content analysis technique. Qualitative content analysis is an analytic tool used to determine the presence of certain words, concepts, themes, phrases, characters, or sentences within texts or sets of texts and to quantify this presence in an objective manner (Bauer, 2000). Directed content analysis (or top down) is more structured than the traditional inductive content analysis approach. It is undertaken with a pre-determined approach to the coding, rather than allow codes to be developed from the data. It is particularly useful when the aim of data analysis is to develop understanding or description of an existing concept, framework or theory (Hsieh and Shannon 2005).

For this secondary analysis, transcripts were read and re-read and codes generated from words, phrases, or sentences where bereaved family members made reference to 'deterioration at end of life'. Codes were examined by all authors (MC, JT, TLS) and agreement was reached as to the key concepts developed from these.

Findings

The secondary analysis identified cues that bereaved family members associated with deterioration of their dying relative in intensive care. The main areas that families spoke of related to: Changes in physiological values seen on the patient's monitor; changes in how their relative looked; and changes in the treatments or interventions that their relative was receiving on intensive care.

Changes in physiology: Cues linked to perceptions of physiological changes appeared to be both visual and auditory, and were stimulated by watching the relative's cardiac monitor and hearing changes in sounds made by their relative. The auditory cues were predominantly linked to changes in respiratory rates and of the noises made during respiration (Table 3).

Table 3: Physiological cues - Visual and auditory

	Examples of comments
Physiological cues: Visual	
Heart Rate	"his heart rate, especially that last twenty four hours obviously it just started to slow down"
Blood pressure and oxygen saturation	"pulse rate dropping. I could see that things were starting to deteriorate as the O_2 sats [oxygen saturations] and pulse rate and the blood pressure which was in her boots"

	"his blood pressure had dropped hadn't it, very low"
	"I could see the sats [saturations] drop"
	"he was on the mask so much that you couldn't have a conversation and that mask increased and got more and more and more as his chest got worse"
Physiological cues: Auditory	
Noises of respiration	"there were several times when we thought she'd drawn her last breath but then it's almost like a rattle and you hear a rattle and then breathing again"
	"struggling and making almost vocal noises to breathe, laboured breathing was, it got worse and better"

Family members also made reference to how their relative looked. These comments were mostly linked to changes in their relative's skin colour, appearance, and responsiveness (Table 4).

Table 4: Changes in how their relative looked

	Examples of comments

Colour	“his hands and toes were starting to go blue”
	“she was navy blue”
	“her colour was dreadful”
	“he was getting greyer and greyer “
	“his hands are blue, his feet are blue”
Appearance	“his arms swelled right up and his face started to look what looked like blister, well skin was peeling back and his hair got all greasy. He should have been waking up but, no I think he’d had enough, poor baby”
Responsiveness	“he did appear dead when we went to visit him”
	“looking at her pupils, unreactive, nothing was happening and I thought, you know, this looks pretty terminal“
	“he never regained consciousness”
	“totally unresponsive but her eyes were open”
	“looking at her pupils, unreactive…”

	"I found my Mother totally unresponsive but her eyes were open, I don't know whether she was conscious, unconscious"
	"her eyes were open but she obviously wasn't alert"

Family members were aware of changes in treatments and interventions for their relative and spoke of either the increasing use of interventions prior to treatment withdrawal, or the removal/reduction of interventions prior to death. This included, for example, oxygen being commenced, the treatments e.g. non-invasive ventilation oxygen being increased, tracheostomy being undertaken, the need for dialysis as "his kidneys started to fail" (SA 001), blood transfusion, being fed artificially, and the presence of "lots of tubes" (SA003).

Cues from more than one failing system were linked in what appeared to be a process of assessment of the ongoing situation. For example, " never came off of his oxygen….he then began to leak from his wounds… we got used to seeing blood *[pressure]* down, going down and then we might say 'is that blood *[pressure]* dropping?" (SA003). In the data, these cues were often used alongside reports of discussions held with doctors and nurses confirming that their relative was not going to survive, and was, in fact dying.

Discussion

The aim of this study was to complete a secondary analysis of primary data that 'tested' the concept of vigilant attentiveness. We propose that findings from this study demonstrate that family members are aware of signs of deterioration in intensive care and that they actively use this information, together with information received from health care professionals, to acknowledge and prepare for the death of their relative.

With the majority of work reporting family members' experiences in intensive care focussing on the need for information movement from health care professionals toward family members (Fox, 2014), there has been limited discussion of the active information gathering by family members at end of life. However, McAdam et al (2008) identified that families act as protectors, facilitators, historians, coaches and voluntary caregivers by their active presence in intensive care with more recently Azoulay et al. (2014) recommending that family members be perceived as active decision-making partners in intensive care.

The profiling of an information-seeking role for family members in intensive care is a relatively novel concept. We propose that vigilant attentiveness, where family members actively watch and monitor changes in their relative's progress and response to interventions, is a process of data gathering to inform understanding, and potentially prepare themselves for imminent death. It is one way they gather data to inform understanding at end of life.

Family members are known to seek cues from patient monitors, the environment (for example, the actions of nursing and medical staff) and "from listening to sounds and noticing surroundings in the ICU…" (Agard & Hardner, 2007:174) These cues appear to be assimilated into an informational source that is triangulated with what doctors and nurses are saying

(Tilden et al., 1999: 437). This process of triangulation is explored in a meta-synthesis (Meeker and Jezewski, 2008) where family members used information and environmental cues as a key component of 'reframing reality' (p:169) in preparation for treatment withdrawal decision-making.

Auditory cues referred to by family members in this secondary analysis as indicating deterioration immediately prior to death are recognised as some of the key terminal events prior to death in non-critical care setting. Signs and symptoms such as respiratory secretions and death rattle are reported (Kehl and Kowalkowski, 2012) and are also identified as being central to information used by nurses to prepare relatives for death in intensive care (Kirchoff et al 2003). Therefore such signs may be recognised as 'social' signs of dying (those signs that are acknowledged by society at large) and therefore may have greater meaning than other signs and may contribute to family members making their own diagnosis of impending death. However, a key issue reported by Agard and Harder (2007) is that such family-acquired cues were not shared with nursing and medical staff. For family members in their study the assessment was a 'silent process' (p:175), which Agard and Harder (2007) suggest led to misunderstandings about prognosis.

Our suggestion that family members may carry out a process of assessment and diagnosis is supported by the work of Plakas et al (2013) who developed the concept of vigilant attendance drawing on Bournes and Mitchells work (op cit). In their grounded theory study, they explored how family members in Greek Intensive Care Units (where visiting is very restricted) monitored changes in their relatives' progress, comparing and contrasting it with information given by medical staff so that family members made their own diagnosis as part of their repertoire of coping mechanisms. So it could be argued that even in the face of limited

contact with visual and auditory cues, family members will try to make sense of what is going on. If this process is silent, then this may be the basis for the reported low levels of family comprehension regarding the patient's condition (Azoulay et al., 2000; Rodriguez et al., 2008), and conflicts between family members and health care team (Fassier and Azoulay, 2010).

Findings from this secondary analysis suggests that family members are active in seeking cues of deterioration by being vigilantly attentive to what is happening (or not happening). Given that this information may not always be shared with health care professionals, we suggest that this area needs consideration when communicating with families. Asking the family what they notice about their relative at end of life, and actively listening (Randall Curtis et al, 2002) to their replies, especially to the words and language used, will enable nursing staff to make an assessment about the family's comprehension about impending death and to probe their 'silent processing' of events. In acknowledging that families may be active gatherers of information at end of life, asking family members to tell us about their assessment of the ongoing situation, along with what their assessment is based on could be a valuable addition to prompts within the ASK-Tell-ASK model (Buckman et al, 1992) or as part of other communication strategies. Engaging with family members in this way may facilitate shared decision-making at the end of life as the information exchange will focus on clarifying the assessment and diagnosis made by the family member(s), potentially in silence, and therefore focus on their reality as opposed to a perceived reality.

Study limitations

Secondary analysis facilitates the re-use of contextually similar data for research purposes and we would argue is both economically and ethically relevant in the current climate of

competition for research funding and concerns related to end of life research. Although participants in the primary research from which this secondary analysis were not specifically asked about whether they noted sign of deterioration in their family member, data indicates that they were aware of changes and did refer to them in their discourse.

Conclusion

Family members actively observe and interpret cues from the intensive care environment as part of a process of being vigilantly attentive to deterioration in their relative at end of life. Exploration of what families members see and hear, or what changes they notice in their relative at end of life, can inform ways of communicating with family members that begins with an assessment of their reality. Tailoring information about the dying trajectory, specific to family need, can better prepare family members for an impending death. This is an important area for information exchange, and one which the bedside nurse can make a major contribution to.

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Competing interests

The authors declare no competing interests.

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